

One step at a time

An interactive learning resource
for faith communities to build a
more supportive environment
for people with dementia
their families and friends



Foreword

Faith in Older People (FiOP) is delighted that you have opened this learning resource, which we have been developing and revising over the past couple of years. We are excited that you and your faith community want to explore, develop and take action to respond better to people with memory, disorientation and confusion problems.

We need to think about fundamental questions, such as:

- **Is our place of worship ‘emotionally safe’?**
- **Are people welcomed not ignored?**
- **Included rather than excluded?**
- **Valued and respected rather than regarded as a nuisance or embarrassment?**

FiOP wants to support and encourage faith communities to include and involve people with dementia and their relatives and

friends in a comfortable and natural way within the place of worship or wherever they live. Our approach is inspired by ‘**In a strange land**’ by Malcolm Goldsmith. You will find references to his work at the back of this guide. To achieve this, issues such as fear, stigma, ignorance and limited communication needs to be addressed and overcome. Everybody with dementia travels a different pathway through the condition - each having their own unique personality and belief system. For many, this diagnosis may have a profound and life-changing impact on their lives. This learning resource aims to help navigate this path alongside the person with dementia, their family and friends.

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Director, Faith in Older People

Acknowledgements

We would like to thank Professor Faith Gibson, Jenny Henderson, Professor Mary Marshall and Lesley Greenaway who wrote and edited the text, and Sandra Carter, Rev. Sue Kirkbride, Chris Levison, James McKillop, Iain Stewart who provided invaluable comments and suggestions.

We are grateful to the TOR Christian Foundation who funded the development of this interactive learning resource. We also value the support and contributions from Alzheimer Scotland, the Scottish Dementia Working Group (SDWG) and the National Dementia Carers Action Network (NDCAN)

Resource guide pdf design and production, videography and editing
by Ian Noble and The Untold MPC

Photos and other images: Pixabay and AdobeStock

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One Step at a Time

Introduction



Introduction

This interactive learning resource is an introduction to dementia. It aims to help clarify the range of language and terminology used, provides some key facts, and signposts useful resources. It will help you to identify some key areas or issues for your faith community to work on.

Further reading: We have included references to source materials which can be found at the back of this resource.

Using the interactive resource

This pdf has embedded links which are in **bold text** - if you click on an item in the contents page, it will

take you there. Click on 'One Step at a Time' in the header and it will return you to the contents page. If you click on a video box, you will be taken to YouTube to view the resource.

You can type your responses into the text boxes. Please remember to '**save as**' to save your changes before you close the document.



One step at a time

Video 

*An introduction to
One Step at a Time*



Focus Areas

This resource has adapted the framework developed in the Joseph Rowntree Foundation report - [Creating a dementia-friendly York](#) - as a tool to help Faith Communities to explore and assess their awareness, knowledge, attitudes and practice. Four key areas were identified: People, Places, Resources and Community, which provide a practical focus for getting started. We also include a focus on Pastoral visits to recognise a particular role that faith communities provide for people in care homes.

1.

People

How do members of your faith community respond to people with dementia?

2.

Places

How can the physical environment of the place of worship enable people with dementia?

3.

Resources

How well can people with dementia use the ordinary resources and opportunities in your faith community?

4.

Community

Do those who support people with dementia communicate, collaborate, share and plan together sufficiently well?

5.

Pastoral visits

Do those who support people with dementia communicate, collaborate, share and plan together sufficiently well?

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2. Getting started



Getting Started

This learning resource is divided into sections. There are sections that are designed to inform your faith community such as the section: Learning about dementia. You can use this section as a handout to share within your group.

Other sections focus on People, Places, Resources, Community and Pastoral visits. These sections provide some information, signpost useful websites and resources and use challenge questions (a bit like the quiz on the following page) to get the conversation going and more importantly encourage you to plan some actions for change.

Steps to change

1. Get the conversation going – use the quiz to get members of your faith community thinking about dementia.
2. Form a small team to look in more detail at how your faith community can become more dementia-friendly.
3. How can we improve? – use the sections in the Guide to explore and assess strengths and weaknesses.
4. Take action to improve the experiences of people with dementia, their relatives and friends.

It's a win-win situation for everyone

We think that by taking a few practical steps you can help people with dementia, their families and friends to feel more comfortable and able to be a continuing part of their faith community, and, help members of your community to feel more confident and less uncertain about dealing with dementia.

Read on for more information, resources and questions to get you thinking and take actions.

You can work through the following steps to develop your actions for change, or dip into the sections of the learning resource that are most useful to you and your faith community.

Starting Point

Knowing where to begin, is often the biggest challenge. so, let's start by using the Quiz below to get the conversation started amongst members of your faith community. Discuss each of the questions and note down the main points. Consider the questions where you have answered 'no' or 'don't know' as these might provide a good starting point for improving support for people with dementia and their families.

● **Is our place of worship 'emotionally safe'?**

Yes

No

Not sure

● **Are all people welcomed, included, valued and respected?**

Yes

No

Not sure

● **Do we know who has dementia in our faith community?**

Yes

No

Not sure

● **Do our members with dementia find it difficult to participate in worship?**

Yes

No

Not sure

● **Is our place of worship physically safe?**

Yes

No

Not sure

● **Is the toilet easy to find and safe to use?**

Yes

No

Not sure

Discussion **Points**

Take a few minutes to make a note of your thoughts after doing the quiz. What aren't you so sure about? What do you need to find out more about?

● **What are you already doing well?**

● **What aren't you so sure about?**

● **What do you need to find out more about?**

Learning about dementia



Learning about **dementia**

The focus for this section is on learning some basic information about dementia, who it affects, how many people are affected, symptoms associated with dementia and how we talk about dementia. We use the term dementia to be clear that we are talking about a number of progressive disorders of the brain.

Some facts and figures

- 1.** Dementia is common. There are a million people with dementia in the UK. Not all have had a formal diagnosis.
- 2.** Alzheimer's disease is the most common type. Some people have vascular dementia and others Lewy Body dementia. There are over 100 different disorders under the umbrella term of 'dementia' and people may have more than one type at the same time.
- 3.** Dementia is mainly a disorder of older age. The older you are the more likely you are to have it, although most of us will not get it and it is not a normal part of aging.
- 4.** According to Alzheimer Scotland (2017) there are around 90,000 people in Scotland with dementia and this is expected to rise. Approximately 3,200 are under sixty-five.
- 5.** 70% of people with dementia live in the community.

Some facts and figures

6. Women appear to be more at risk than men.
7. Everyone's pathway through the condition is different and depends on many factors such as support, the person's own and their family's coping skills, mental and physical health.
8. Dementia symptoms frequently lead to other consequences such as feeling low, bewildered or depressed. They and their families and friends can become increasingly isolated.
9. Dementia affects people from all countries, cultures and intellectual abilities, although there are of course extra problems if you are growing old in an adopted country. For example, you may forget your second language and revert to the one you learned first.

Discussion Points

Take a few minutes to make a note of your thoughts about these facts and figures.

- Did any of this information surprise you?

What are common symptoms of dementia?

inability to keep track of time and place

difficulty finding and using words, and taking longer to take in what is being said

memory difficulties, especially recent or short-term memory

difficulty understanding conversation

sensory problems, which means people can misunderstand what they are seeing

reduced ability to carry through decisions and make plans

being distressed and frustrated often because people are physically unwell, too hot, too cold, in pain, can't make themselves understood and/or have difficulties interpreting their surroundings

reasoning difficulties

written and reading skills may diminish

difficulty learning new skills



Discussion **Points**

- **What are your experiences of dementia? Are you surprised to find out about some of these symptoms?**
- **Might these symptoms explain some of the issues people with dementia have experienced at your faith base?**
- **What do you need to find out more about?**

Talking about dementia



Dementia is the term that many people with dementia prefer, but that does not mean that everyone likes using it.

There are many words which people use to describe dementia such as Alzheimer's, memory problems, senility, confusion, mentally infirm, cognitive loss.

Many people find the term dementia difficult, frightening and a negative word. It seems to imply we are talking about madness rather than a common set of brain disorders.

Words like senility mean little except ageing so are not helpful. Confusion is a symptom rather than a disorder and mental infirmity is so general as to be unhelpful.

Some people prefer to say memory problems. If it is understood that this refers to a progressive condition, meaning it will get worse with time, then does the term used matter? The important thing is to be able to talk openly about it.

Family members do not always like being called 'carers' but like to feel that their identity as a husband/wife/mother/daughter/son/partner/friend continues to be recognised.

If you speak another language, there may be problems with finding an appropriate term to use. Most countries have an Alzheimer Society so check their web site and see what has been agreed.

Concerns about dementia

We are not alone, most of the anxieties we have about dementia are shared by others in our faith community:

Our fears

we are all afraid of getting dementia and about losing capacity and loss of control over our lives. We can also be afraid of the apparently unpredictable behaviour of some people with dementia.

Our concerns

about not being able to make sense of what the person is saying and assuming they have nothing of value to contribute.

Our experiences

of friends and family will influence what we think about dementia. Often, we only remember the bad things and the advanced stages of the illness.

Our assumptions

people with dementia no longer have a spiritual dimension to their lives.

Our lack of knowledge and skills

we need to know more about dementia and about skills of communication and coping.

These concerns can be reduced through discussion, sharing knowledge and skills and working together to make the whole environment of your faith community dementia-friendly for everyone.

Key points to remember

- People can and do change with dementia, but they are still people and have a lot to teach us.
- Remember when you have met one person with dementia you have met one person.
- The impact on family and friends cannot be underestimated.
- For many people with dementia, their abilities to be creative, to enjoy spiritual fulfilment and to have relationships are often the last things to be affected.
- Remember the focus is on PEOPLE: PEOPLE with dementia, and not people with DEMENTIA.

Additional Resources

If you want to learn more about dementia, [Alzheimer Scotland – Action on dementia](#) provides a wide range of information and support including a 24-hour helpline.

A very readable book by somebody with dementia is Wendy Mitchell's book 'What I wish people knew about dementia.' (Bloomsbury Publishing 2021)

Age Scotland host a range of useful resources which can be [accessed online](#).

Another useful resource is available from the Alzheimer's Society: [Alzheimer's Society – Making your community more dementia-friendly](#)

Action for change: People



Action for change: **people**

In the People section there is a focus on how members of the faith community respond to and support people with dementia.

It is important to understand that we are more at risk of dementia as we get older, so there are almost certainly people with dementia in your congregation. There may be tell-tale signs of someone who is not coping, but there may not. Unless you have made it normal to talk about worries relating to loss of memory and about getting a diagnosis, it is unlikely that you know all the people who have dementia in your Faith Community.

You can make a start by using the 'Learning about dementia' section of this learning resource (p.10-17) as the basis for discussion. There are also fact sheets available from **Alzheimer Scotland** on: What is dementia? Alcohol related brain damage; Alzheimer's disease; dementia with Lewy Bodies and vascular dementia.

You might want to watch some short films together and have a discussion. Here is a suggestion- just click in the box to view a short online film called '**What is dementia?**' which was produced by the Alzheimer Society:



Dementia Voices also have short film clips by people with dementia about their experiences of living with dementia which may be helpful.

The importance of faith to individuals should always be at the forefront of our minds.



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Communication

There are some practical things that members of your faith community can do to improve how they communicate with people with dementia.

“**Did you enjoy your lunch?**” as opposed to “**What did you have for your lunch?**” doesn’t put a person with dementia under pressure to remember and may lead to a conversation about lunch.



- Find the right place where you and the person with dementia will feel comfortable.
- Introduce yourself.
- Sit in a quiet place with good lighting.
- Learn to observe and respond to body language and non-verbal messages.
- Ask short questions one at a time. Try not to ask for facts. Use prompts.
- Allow time for the person to respond.
- Be patient and don't rush in to complete the person's sentences.





Informal caring for an individual with a diagnosis of dementia

A diagnosis of dementia for an individual may cast a long shadow affecting all those involved. Family and friends may struggle with the unexpected course their lives have taken. They may be faced with multiple losses; the loss of a life they had planned together, a change in relationships and a fear of the future. However, there are countless family carers who devote their lives to caring for their parent, husband, wife, partner, or friend. They may experience a range of emotions; love, a sense of duty, guilt, anger to name but a few. For some it may be a rewarding experience but not for all.

Some informal carers do not like the word 'carer' because first and foremost they are a wife, husband, son, daughter, partner, or friend. They are care givers rather than formal paid carers with a long-standing relationship with the person.



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[Carers UK Scotland](#) provides a helpful list of some implications of caring.

Discussion Points

The statistics express the enormous amount of unpaid care given by family and friends but also the impact on their health, employment, and the additional problems faced by people in underrepresented groups.

Think about members of your congregation who are family carers of people with dementia. You may be able to talk to them the about their role and responsibilities. If not, try and 'walk in their shoes'. Make a note of what you think these responsibilities might be:

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Think about this hypothetical 'job description'.

WANTED

An informal carer (relative or friend) to look after someone with dementia at home.

An individual is required to carry out a physically and medically exhausting job which may include heavy lifting.

Applicants should be capable of working alone for indefinite periods. The successful candidate will be expected to be on call 24 hours a day, seven days a week, and will only receive holidays if they are lucky or can afford to pay for someone to cover for them.

Pay will be either at a rate that is below the official poverty line, or non-existent. Social status to the job is low. They must have the ability to negotiate with multiple services - both in health and social care.

Applicants are expected to show evidence of a sense of humour, along with limitless patience. No training is provided. Transport may be necessary.

NB: Some of these experiences may be emotionally draining!

When the responsibilities of an informal carer are presented as a job description how does it make you feel?

What informal carers tell us:

- Caring can 'creep' up on a family member or friend. Sometimes they feel they must take on the role out of a sense of duty, for others it is love.
- Many carers are part of the sandwich generation, not only caring for the older generation but also their grandchildren.
- Caring can be very lonely - friends and even sometimes some members of family stop visiting.
- Informal carers would like to be effective partners in care, but this is often thwarted by failures in communication.

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- At critical points and in specific ways they can be excluded by staff, and requests for helpful information, support and advice are not heard.

What could help?

- Society's greater recognition of the informal carer role
- A recognition of the need for greater financial support to fulfil the role.
- The concept of a triangle has been proposed by many carers who wish to be thought of as active and equal partners within the care team.
- Training and support groups play an important role.

Source: <https://carers.org/downloads/resources-pdfs/thetriangleofcare-thirdedition.pdf>



One step at a time
Action for change: People

Video 

Underpinning the spiritual content in our lives using a human rights approach

Faith in Older People

How can your congregation help?

Reflect on ways your congregation could make a difference. Look in the small places. This may be supporting the individuals spiritual needs, providing a listening ear or perhaps practical help.



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Action for change: People

A warm welcome

Video 

Faith in Older People

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One step at a time
Action for change: People

Faith in Older People

Training

Video 

The video thumbnail features a background image of wooden directional signs with arrows pointing in various directions, set against a light, hazy sky. The text is overlaid on the left and right sides of the image.



One step at a time
Action for change: People

Faith in Older People

Video 

Jeanette talks about activities at her church and the need for further training

This video thumbnail is similar to the first one, with a background of wooden directional signs. The text is positioned on the left and right, and includes a specific description of the video content.

Key points to remember

- Families and friends often have a lot of expertise in what makes a difference and may be pleased to share ideas if asked.
- Use videos, websites, handouts and challenge questions to get conversations about dementia going.
- Good communication is good for everybody.

What can we do to improve?

Challenge questions provide a stimulus for your faith community to think in more detail about how you respond to and support people with dementia.

- **Discuss** each question and share views on the current position in your faith-community.
- **Decide** your shared answer to each question yes/no/don't know.
- **Plan actions.** Share ideas for change and select 1 or 2 actions that will make a difference.
- **Review progress.** Set a time scale and review progress before moving on to your next task.

PEOPLE Challenge Questions: ask yourselves

- **Do all the members of our community understand what dementia is?**

Yes No Not sure

- **Do we know who has dementia in our faith community?**

Yes No Not sure

- **Are people comfortable talking about dementia just as they would any other illness or disability?**

Yes No Not sure

- **Do we all understand why relatives and friends might be unwilling to talk about dementia?**

Yes No Not sure

- **Are the family members and friends, who are looking after someone with dementia, supported by our faith community?**

Yes No Not sure

- **Do we know who used to participate in our faith community but who no longer comes along because of their dementia?**

Yes No Not sure

- **Have we discussed why the behaviour of some of our community who have dementia causes difficulties and how we might best help?**

Yes No Not sure

- **Have we discussed how we could support people with dementia who live in our communities but are not necessarily part of our faith community?**

Yes No Not sure

Action **plan:** people

What actions will we take?

Who will do what?

When will we review our progress?

Additional **Resources**

- Bryden, C. (2005) *Dancing with Dementia*. London: Jessica Kingsley Publishers.
- [Communicating with Someone Who Has Dementia: 12 helpful hints.](#)
- [Dementia Voices](#)
- [A Walk Through Dementia](#)

For Informal **Carers**

- Alzheimer Scotland: helpline@alzscot.org - 0808 808 3000
- Age Scotland helpline: 0800 12 44222
- Carers UK helpline: 0808 808 7777

Action for change: Places



Action for change: **places**

In the Places section there is a focus on how the physical environment supports people with dementia.

Most older people understand that they need more light and try to ensure they sit where there is light. If you have dementia you may not be able to work this out, so we need to ensure that our buildings are sufficiently light. Aim for twice the light needed by someone of twenty-five.



The older eye also needs a lot more contrast in tone for things to be visible. A key issue is the edges of steps, so people can see them easily.

Many older people, men and women, need to go to the toilet more often and more quickly. Toilets need to be easy to find. You may have a toilet that you consider is easy to find but remember that people with dementia may not remember where it is.

People with dementia do not always have the ability to work out how to get into your place of worship if the main door is not in use. Once inside they can also become uncertain about which door to go through. Exits also need to be clearly signed and easy to find.

Signage is important for people with dementia:

- A sign should have words and a picture/drawing because many people with dementia can no longer read.
- The first letter on the sign should be a capital, then followed by lower case as recommended by the RNIB
- Letters should be big enough for someone with poor vision to be able to read them easily.
- The word and picture should contrast well with the background which should contrast well with the door/wall.
- The sign should be mounted no higher than 1.2 meters from the floor because older people tend to stoop a bit and need crucial information at a lower level.



One step at a time
Action for change: Places



Video



*Thinking about
the physical environment*

Key points to remember

Finding the way in is especially important if people are to feel comfortable and relaxed when they arrive.

Consider whether people who are welcoming others into the building should wear clear name badges to make it easier for people to remember names.

Make toilets easy to find and safe to use.

What can we do to improve?

Challenge questions provide a stimulus for your faith community to think in more detail about how the physical environment supports people with dementia.

Discuss each question and share views on the current position in your faith community.

Decide your shared answer to each question yes/no/don't know.

Plan actions. Share ideas for change and select 1 or 2 actions that will make a difference.

Review progress. Set a time scale and review progress before moving on to your next task.

PLACES Challenge Questions: ask yourselves

- **Is our place of worship physically safe? Older people need twice the levels of light of younger people. Are the edges of steps clear to see?**

Yes No Not sure

- **Are there suitable places for prayer and worship?**

Yes No Not sure

- **If you use an alternative place for worship, do you have familiar spiritual cues: objects, music, rituals and words to help the person understand what is going on?**

Yes No Not sure

- **Is the toilet easy to find and safe to use? Older people need to find the toilet quickly. Consider the signage.**

Yes No Not sure

- **Are the entry and exit doors to the building easy to find? Sometimes side doors are used and are not always easy to find.**

Yes No Not sure

- **Are our faith community worship or social activities very noisy? Many older people find a lot of noise means they cannot follow a conversation.**

Yes No Not sure

- **Have we considered how people see things? Many people with dementia can no longer easily interpret what they are seeing. For example, they can perceive a step when there is strong contrast between two adjacent floor coverings.**

Yes No Not sure

- **Are there quiet, well-lit places for conversation?**

Yes No Not sure

Action **plan**: places

What actions will we take?

Who will do what?

When will we review our progress?

Additional Resources

For people who are really interested in enabling design for people with dementia, the Alzheimer's Disease International Report 2020 is full of really good material: **Design, Dignity, Dementia: dementia related design and the built environment.**

Another useful resource is PAS 6463:2022 produced by the British Standards Institution (BSI): **Design for the mind - neurodiversity and the built environment - Guide.** This guide covers a range of conditions like autism as well as dementia.

There are very useful ebooks produced by **HammondCare:**

- **Toilet Talk (2nd Edition): Accessible design for people with dementia**
- **Talking sense: living with sensory changes and dementia. Agnes Houston with Julie Christie**
- **A breath of fresh air Annie Pollock**
- **Acoustics in aged care Richard Pollock**

It can be a good idea to audit the dementia friendliness of your church. A simple tool designed for people with dementia to use, but which would also be useful as a basic starter, is one of the resources provided by **DEEP.** It is called **Audit checklist: is this INSIDE space dementia-inclusive.**

There are comprehensive audit tools for sale such as the one produced by the University of Stirling: Environments for ageing and dementia design assessment toolkit (EADDAT) or by HammondCare **Designsmart.**

Other useful resources include:

- Fuggle, L (2013) Designing interiors for people with dementia. Stirling: Dementia Services Development Centre.

Action for change: Resources



Action for change: **resources**

In the Resources section there is a focus on whether there are enough services and facilities for people with dementia and if these are supportive and appropriate to their needs. Think about how well people can use the ordinary resources in the faith community.



Worship

Some people with dementia can behave in a way that others struggle to understand; they may have a short concentration span or be unable to follow what is going on and disengage from the service leading to non-attendance.

To ensure inclusion, it is helpful to understand the person's previous worship and ritual patterns and their favourite Bible passages/verses. There is also the potential to introduce

short services with familiar texts and hymns.

Music has been shown to be a vital way of engaging people with dementia and the use of familiar tunes and words are important and a real way of giving enjoyment. Faith traditions with a strong sense of ritual in their practices will be easier for people with dementia to follow so think about how you could develop this.

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One step at a time **Action for change: Resources**



Video 

*Margaret lives with dementia.
Here, she talks about
helpful approaches and resources.*

One step at a time **Action for change: Resources**



Video 

*Geoff lives with dementia.
Here, he talks about
helpful approaches and resources.*

One step at a time **Action for change: Resources**



Video 

*Planning for inclusion
and embracing technology*

One step at a time **Action for change: Resources**



Video 

*Kenny & Phil discuss
a few things that can make
a big difference*

One Step at a Time

Participation

Confidence and self-esteem make a big difference to how well a person with dementia can feel included and able to participate. There may also be several aspects that can be a barrier to participation: sensory loss either visual or hearing, problems of understanding what is going on, loss of concentration, anxiety of family members.

Help someone with dementia to participate by:

- Introduce yourself even if you have known the person all your life – do not expect them to remember. For example: ‘Hello, I am Susan Smith. We were both in the choir and your name is ...’
- Facing the person in a good light and ensure that they can see your face so the person with dementia can get clues from your facial expressions.
- One conversation at a time will help, group conversations require nimble understanding and quick thinking; qualities likely to be impaired for the person with dementia.
- Can their favourite Bible passages or verses services be included in versions they are familiar with and hymns sung with familiar tunes?

“As I lose an identity in the world around me, which is so anxious to define me by what I do and say, rather than who I am, I can seek an identity by simply being me, a person created in the image of God. My spiritual self is reflected in the divine and given meaning as a transcendent being.”

Bryden, C. and MacKinlay, E., 2003. Dementia—a spiritual journey towards the divine: A personal view of dementia. *Journal of Religious Gerontology*, 13(3-4), pp.69-75.

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Activities

When someone has dementia, it is not unusual for them and the person who cares for them to become very isolated. Going out to a café can be difficult if the person gets confused or cannot manage the toilets. Friends can melt away.

Social events where people can relax because they are confident that everyone knows about dementia and will cope with anything that arises can be a real treat. These clubs can have a function like a singing group, or they can just be a time for a tea and a chat. You may already have all sorts of groups going on, at which people with dementia would be welcome – perhaps at a special table, provided it feels inclusive or with a little extra support nearby.

Key points to remember

- You may already have all sorts of groups going on, at which people with dementia would be welcome – perhaps at a special table, provided it feels inclusive or with a little extra support nearby.
- Involve some extra volunteers to support the person with dementia to participate.

“As I travel towards the dissolution of my self, my personality, my very “essence”, my relationship with God needs increasing support from you, my other in the body of Christ.

Don't abandon me at any stage, for the Holy Spirit connects us. It links our souls, our spirits - not our minds or brains. I need you to minister to me, to sing with me, pray with me, to be my memory for me.

The liturgy, familiar hymns and choruses, the Lord's Prayer - these are ways in which you can help me join with you in our walk with God. Never dismiss me because I don't understand.”

Bryden, C. and MacKinlay, E., 2003. Dementia—a spiritual journey towards the divine: A personal view of dementia. *Journal of Religious Gerontology*, 13(3-4), pp.69-75.

What can we do to improve?

Challenge questions provide a stimulus for your faith community to think in more detail about how well people with dementia can use the ordinary resources in the faith community.

Discuss each question and share views on the current position in your faith community.

Decide your shared answer to each question yes/no/don't know.

Plan actions. Share ideas for change and select 1 or 2 actions that will make a difference.

Review progress. Set a time scale and review progress before moving on to your next task.

RESOURCES Challenge Questions: ask yourselves

- **Do our members with dementia have difficulties relating to worship or appear to be unable to engage with previously held beliefs?**

Yes

No

Not sure

- **Do our members with dementia have difficulties relating to or participating in other activities such as social events?**

Yes

No

Not sure

- **Do we have activities such as a club for people with dementia, their families and friends?**

Yes

No

Not sure

- **Do we include people with dementia and their families in existing activities?**

Yes

No

Not sure

- **Do we know who we could turn to for help with difficulties? For example, choosing a couple of people in our faith community who are identified as our dementia leaders.**

Yes

No

Not sure

- **Is there an expert in our community who might be willing to be called upon from time to time?**

Yes

No

Not sure

- **Have we used the internet to find useful resources and training materials or have we bought books or guides to help us?**

Yes

No

Not sure

- **Have we considered providing the experience of worship online for people who are confined to their home or a care home?**

Yes

No

Not sure

Action **plan**: resources

What actions will we take?

Who will do what?

When will we review our progress?

Additional Resources

- Kelly, E. (2012) *Personhood and Presence: Self as a resource for spiritual and pastoral care*. London: Bloomsbury Publishing.
- Killick, J. (2008) *Dementia Diary: Poems and prose*. London: Hawker Publications.

Action for change: Community



Action for change: **community**

In the Community section there is a focus on how well people in our faith community who support people with dementia communicate, collaborate and plan together.



Collaborations to share ideas and experience could include:

- Training days, seminars with speakers
- Sharing ideas to learn what has worked and what has not
- Sharing of experts, resources such as books, packs, training materials.

A good starting point may be to have an awareness-raising session for those interested. You may want to include a speaker such as a local health professional, old age psychiatrist, someone from Alzheimer Scotland services, or someone from a care home or housing service that specialises in dementia care. You may know of a family member or someone with dementia who may be prepared to share their experiences. It is also a good idea to have information leaflets available for example, ensuring that people know there is a 24-hour helpline and other key fact sheets. Be clear what the purpose of the session is, what benefits will be for those who attend and be sure to allow enough time.

One Step at a Time

Find out what specialist services are available in your area and how other faith communities support people with dementia.

Alzheimer Scotland gives a breakdown of their own services for each council. It is worth contacting them to get a list of what is available and then supplementing it

with other local knowledge gained from council/ NHS websites and your own networks.



One step at a time
Action for change: Community

Video 

 *Mayfield-Salisbury Church:
A dementia-friendly approach*

Faith in Older People provides all sorts of seminars and meetings and its newsletter will alert you to events being organised by other related organisations.

Alzheimer Scotland supports organisations working with people with dementia. They have experience and advice in developing dementia friendly communities.



One step at a time
Action for change: Community

Video 

 *Mayfield-Salisbury Church:
A walk through the building*

Key points to remember

- Many faith communities have dementia support groups and may be pleased to share their experience.
- Find out what services are available in your area and identify knowledgeable people who are willing to help you.
- When organising a dementia awareness raising session be clear about your aims, who it is for and what benefits you hope to achieve.

What can we do to improve?

Challenge questions provide a stimulus for your faith community to think in more detail about how well your faith community communicates, collaborates and plans together.

Discuss each question and share views on the current position in your faith community.

Decide your shared answer to each question yes/no/don't know.

Plan actions. Share ideas for change and select 1 or 2 actions that will make a difference.

Review progress. Set a time scale and review progress before moving on to your next task.

COMMUNITY Challenge Questions: ask yourselves

- **Do we have a way of sharing concerns and expertise on dementia within our local community?**

Yes

No

Not sure

- **Do we know what dementia services there are in the neighbourhood?**

Yes

No

Not sure

- **Do we have links with any local agencies, services or professionals who might like to be involved?**

Yes

No

Not sure

- **Do we know about local and national dementia plans?**

Yes

No

Not sure

- **Are there other places of worship locally we can team up with to better meet the spiritual needs of the people with dementia from our community?**

Yes

No

Not sure

- **Are there organisations which we could join that would provide ideas, training and possibly support?**

Yes

No

Not sure

Action **plan**: community

What actions will we take?

Who will do what?

When will we review our progress?

Additional Resources

- Magnusson, S. (2015) *Where Memories Go - Why dementia changes everything*. London: Two Roads
- Kerr, D. (2015) *Singing Groups for People with Dementia. A guide to setting up and running singing groups in the community and residential setting*. Gloucester: Choir Press.

Action for change: Pastoral visits



Action for change: pastoral visits

Pastoral care is about companionship, comfort and support. It is often provided in the home or care home when someone can no longer attend their place of worship. If requested, a pastoral visitor may pray or sing with a person. It is important that the pastoral visitor appreciates that although the person may be in the moderate to advanced stages of dementia there will be a huge variation in how the person communicates. Some will have relatively good verbal skills and however rambling and incoherent their stories, they will be keen to chat and give much wit and wisdom. Whilst others will have relatively little verbal communication skills left and will be

relying on the visitor's behavioural and emotional content to make a connection. Greeting the person with a smile, good eye contact, touch and introducing yourself even if you have known the person for years will do much to ensure the visit is successful. Concentrating on topics from the past may help even if this is repeated at each visit. It should not matter that the person with dementia cannot reply. The sound of a kind voice can be comforting. It is also important to know when not to talk but just listen to the person; they need to tell their stories even if they are difficult to understand.



Visitors need to judge whether the person with dementia is relaxed with the visit. If the visit is not going well then it may be possible to distract the person, for example going for a walk or having a cup of tea. It maybe that it is not the best time of day for the person or maybe the visitor is just not the right person and some other member of the pastoral team would work better.

One Step at a Time

It is important to think of ways of engaging with all the senses of sight, sound, taste, smell and touch. Some people like to be shown pictures, so some photographs of the place of worship may be very helpful. Introducing something from nature that may link to the season may be successful especially if the person can feel or smell the item; examples include leaves in the autumn, the smell of freshly cut flowers etc. Music may help especially if the type of songs and melodies are particularly significant for the person. Familiar passages from sacred texts or prayers may also have a calming effect.

When people with dementia become too impaired to recognise or even acknowledge a visitor, it can be very dispiriting to visit. But it is as important as it would be with anyone who is approaching the end of life. Just being there and being a kindly and comforting presence is surely worthwhile. Touch, as we have said above, is a sense that lasts to the end and is a fundamental need throughout our lives. Most people with dementia will appreciate a hand or arm held gently and to feel that you are close and comfortable in their company but find out first.

Key points to remember

- It is important not to be afraid of silence, but just to 'be' with the person.
- Think of ways to engage with all the senses of sight, sound, taste, smell and touch.
- Greeting the person with a smile, good eye contact, touch and introducing yourself will do much to ensure a successful visit.

What can we do to improve?

Challenge questions provide a stimulus for your faith community to think in more detail about how pastoral visitors are supported.

Discuss each question and share views on the current position in your faith community.

Decide your shared answer to each question yes/no/don't know.

Plan actions. Share ideas for change and select 1 or 2 actions that will make a difference.

Review progress. Set a time scale and review progress before moving on to your next task.

COMMUNITY Challenge Questions: ask yourselves

- **Are our pastoral visitors confident and comfortable about spending time with people with dementia when conversations may be fragmented, limited or non-existent?**

Yes No Not sure

- **Do our pastoral visitors know how to deal with hearing/visual impairment as well as ‘cognitive’ impairment? Are they comfortable about using some degree of touch?**

Yes No Not sure

- **Are our pastoral visitors able to judge when it is helpful to have other people present in the conversation such as family members and friends, staff or other residents? Are they confident about what to do in these situations?**

Yes No Not sure

- **Are our pastoral visitors confident and comfortable about talking to relatives and friends who maybe struggling to cope with the move of their family member to a hospital or care home?**

Yes No Not sure

- **Do pastoral visitors see the value and importance of continuing to visit when outward evidence of their visits is difficult to measure, and they may not even be recognised?**

Yes No Not sure

- **Many staff in care settings struggle to meet the spiritual needs of people with dementia. Are there ways we can involve or support them?**

Yes No Not sure

- **Have we considered having a conversation with the manager about raising awareness amongst the staff so that our visits are part of the model of care and peoples’ care plans?**

Yes No Not sure

Action **plan**: community

What actions will we take?

Who will do what?

When will we review our progress?

One step at a time: What next?



One step at a time: what next?

At the start of this learning resource we invited you to think about these questions:

Is our place of worship emotionally safe? Are people welcomed not ignored, included not excluded, valued and respected rather than regarded as a nuisance and an embarrassment?

First you need to be able to talk about dementia from a position of some knowledge and understanding, and then attitudes change and finally behaviour. This is the core of dementia friendliness.

It is very common that families and friends are embarrassed to bring the person with dementia to worship or social events. This is where ‘dementia friendliness’ is tested. If your Community is really dementia friendly, then families and friends should feel able to talk about dementia and feel that others really understand. They should be able to discuss what would be best for them and for the person with dementia without embarrassment. The solution for each person with dementia will be different – and it will change as the condition progresses – but you will know how dementia friendly your Community is when this is no longer a problem for most people.

As you have worked your way through this resource, you’ve been encouraged to challenge yourselves, discuss, plan and review.



One Step at a Time

Please keep a copy of these notes. They are useful waymarkers as you progress, one step at a time. They can serve as a reminder of how far you have come, a prompt to keep nudging forward and a celebration of achievements. That said, the more you discover, the more you'll find there is still to explore and understand! So, every now and again, ask yourselves these questions again.

It's a win: win situation – Get it right for people with dementia and you get it right for everyone.

Finally, tell us how you are getting on
FiOP is keen to hear from your faith community about what you are doing to improve the support for people with dementia, their family and friends. Also tell us about how this learning resource has helped you and how it can be improved.

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10.
**One step at a
time:
More
information
and resources**

Resource Library

Alzheimer Scotland – Action on dementia – provides a wide range of information and support including a 24-hour helpline <https://www.alzscot.org/>

The 24-hour Dementia Helpline is a freephone Scottish service for people with dementia, carers, relatives, professionals, students and anyone concerned about dementia. https://www.alzscot.org/services_and_support/dementia_helpline

This article makes the distinctions between the different ways we communicate as well as providing communication tips. **Communicating with Someone Who Has Dementia: 12 helpful hints.** http://www.alzscot.org/assets/0002/1407/12_Helpful_Hints_lo-res.pdf

This information sheet outlines the different approaches to communication depending on the stage of the illness: **Tips for successful communication at all stages of Alzheimer's disease** http://www.alz.org/national/documents/brochure_communication.pdf (April 2016)

Alzheimer Scotland dementia friendly toolkit:
http://www.alzscot.org/dementia_friendly_communities

Alzheimer's Society – provides a wide range of information and support
www.alzheimers.org.uk

Have a look at the following information and **fact sheets about communication:**
<https://www.alzheimers.org.uk/about-dementia/symptoms-and-diagnosis/symptoms-communicating-and-language>

There is also information on **Making your community more dementia-friendly**
<https://www.alzheimers.org.uk/get-involved/dementia-friendly-communities>

Crossreach is a Church of Scotland organisation that runs Heart for Art programme Scotland.
<https://www.crossreach.org.uk/find-service/care-older-people/getting-creative-dementia>

Dementia Voices have short film clips developed by people with dementia about their experiences of living with dementia. <https://www.dementiavoices.org.uk/>

Livability website includes a leaflet giving top ten tips on worship, prayer, communication, buildings and dementia friendly communities:
<https://livability.org.uk/resources/dementia-inclusive-church/>

One Step at a Time

Methodist Church in Scotland **Growing dementia friendly churches – A practical guide**
https://www.mha.org.uk/files/3814/0931/8295/Growing_Dementia_Friendly_Churches.pdf

Playlist for Life is a charity dedicated to creating ways to ensure that music continues to play a role in making connections to people with dementia. It gives advice on creating a playlist and provides research evidence which supports the importance of music for people with dementia.

<http://www.playlistforlife.org.uk/#2839>

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One Step at a Time

One Step at A Time (2023)
Produced by Faith in Older People
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Website: www.faithinolderpeople.org.uk
A Registered Charity in Scotland SC038225